Boston Sunday Globe

December 17, 2017

SUZANNE KREITER/GLOBE STAFF (UPPER LEFT); SCOTT LAPIERRE/GLOBE STAFF (ABOVE); KIM RAFF FOR THE BOSTON GLOBE (LEFT)

Clockwise from top left, Ben Gabelman got an injection of Spinraza from Dr. Kathryn Swoboda at Massachusetts General Hospital; each dose of the drug costs $125,000; Colin English of Utah with his brother, Jaxon.

THE NEW PRICE OF HOPE

The biotech revolution is cracking the genetic code of one rare disease after another, creating drugs that are a blessing to patients, but command huge prices that deeply strain the health system.

By Robert Weisman and Jonathan Saltzman
GLOBE STAFF

It would have been just another midsummer day of activities and camaraderie at church camp, except that Colin English hadn't felt right since he rolled out of his bunk bed.

His legs had felt weak, and at first he couldn't move them. Only with the help of campmates did the 12-year-old make his way to a morning assembly, walking hesitantly until he abruptly stumbled and fell.

"My legs just stopped working," he recalled.

He couldn't know in that moment, a year ago July, what had struck him. But his parents had reason to fear, and soon Colin would, too.

It was his turn.

After months of tests, he would be diagnosed with spinal muscular atrophy, the leading genetic cause of death in infants — and the disease that had killed his two sisters. Taleah died two days before her fourth birthday when Colin was a toddler; Tabitha succumbed eight years later at the age of 5. Their memory, and loss, haunts the family.

Colin had a less severe form of SMA. Most with the worst form die before age 2, never able to sit up and progressively robbed of the ability to eat and, finally, breathe. The condition attacks the neurons that control muscle function, and its course is inexorable.

But for Colin, there was reason for hope.

There had been no effective treatment when Taleah and Tabitha were stricken. SMA was a so-called "orphan" disease with too few cases — about 10,000 nationally — to draw

SPINRAZA, Page A8

Opioid abuse fuels alarming reemergence of HIV cases

The numbers are relatively small but clearly rising among needle sharers

By Felice J. Freyer
GLOBE STAFF

The opioid epidemic is threatening to trigger a resurgence of HIV in Massachusetts, potentially undoing decades of work that had made the state a national leader in stopping the spread of the virus.

A sharp uptick in new HIV cases among injecting drug users, who often share needles, has raised worries among health officials. They fear Massachusetts could experience an outbreak like the 2015 calamity in rural Scott County, Indiana, where one person introduced the virus into a network of drug users, and within four months more than 180 had become infected.

"It would be a little early to say we have an epidemic on our hands, but we're primed for it," said Dr. Jenifer L. Jaeger, interim medical director of the Boston Public Health Commission.

The numbers in Massachusetts remain small — 78 new diagnoses of HIV so far this year among people who inject drugs. But at this time last year, only half as many cases had been iden-

HIV, Page A5

Trump driven to erase all things Obama

Through appointments and regulations, if not new laws, he's taking down a legacy

By Victoria McGrane
GLOBE STAFF

WASHINGTON — If one thing has defined President Trump's approach to policy in his first year in office, it is his extraordinary zeal in trying to erase the accomplishments of his predecessor, Barack Obama.

ANALYSIS

From the petty (axing the White House bike-sharing station) to the profound (the Affordable Care Act), Trump has sought to roll back Obama achievements across the waterfront.

Some of those attempts have failed — the health law lives, though one key piece of it, the individual mandate, appears about to go away — but the intensity of Trump's effort to bust up his predecessor's legacy hasn't ebbed a bit.

And he has had some real successes: Through executive actions, regulatory rollbacks, and personnel appointments — especially to the judicia-

ANALYSIS, Page A14

A matter of degrees

Sunday: Still cool, flurries. High 28-33. Low 21-26.

Monday: Clouds, warmer. High 35-40. Low 30-35.

High tide: 10:27 a.m., 11:01 p.m.

Sunrise: 7:08 Sunset: 4:13

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VOL. 292, NO. 170
*
Suggested retail price
$4.50

Bostonian of the Year

Dr. Ann McKee's work on CTE has shaken up the NFL and may change football forever. **Globe Magazine.**

How should one write about the work of artists guilty of sexual harassment? That's the question for the Globe's critics in the **Year in Arts 2017. G1.**

He built a new life, but the old one found him

Natalino Gomes was working 2 jobs, dreaming of what could be. Then a masked man walked in.

By Maria Cramer
GLOBE STAFF

When Natalino Gomes dreamed of a life beyond Dorchester, beyond the fear and violence that swirled around him, he pictured Miami.

Sometimes, he imagined himself on his wedding day — on a warm beach beside a calm, blue-green sea. His suit was white, a Louis Vuitton. He and his bride were surrounded by family and friends.

The daydream felt safe and beautiful and, most of all, far from Bowdoin-Geneva, the section of Dorchester that had been his home since he was 14.

One September night in 2012, when one of his best friends was nearly killed by a gunman, Gomes was ready to make his dream a reality and take the next plane out of Boston.

"Now!" he said a few days after his friend's shooting. "I want to move on now, not later. Because maybe later, it

GOMES, Page A6

Natalino Gomes was killed at Peguero's Market in Dorchester.

Barry R. Sloane Marshall M. Sloane Linda Sloane Kay

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